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Guidelines for the Care of People with Spina Bifida Research Priorities

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Disclosures

- No conflicts of interest to report.
- This project is supported by:
    - The Spina Bifida Association
    - Spina Bifida Collaborative Care Network
    - The Centers for Disease Control and Prevention

- Prior guidelines published in 2006
- 14 sections

Prenatal Counseling

Care Coordination

Psychosocial Development

Learning & Education

Family Functioning

Sexual Development

Independent Living

Women's Health

Latex

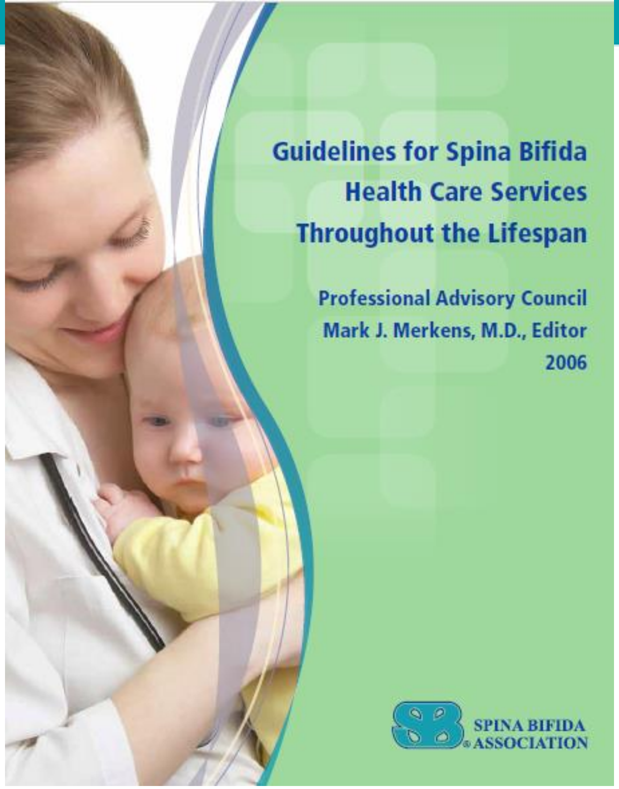
Skin (Integument)

Bowel

Urology

Orthopedics & Mobility

Neurosurgery



Guidelines for Spina Bifida
Health Care Services
Throughout the Lifespan

Professional Advisory Council
Mark J. Merkens, M.D., Editor
2006

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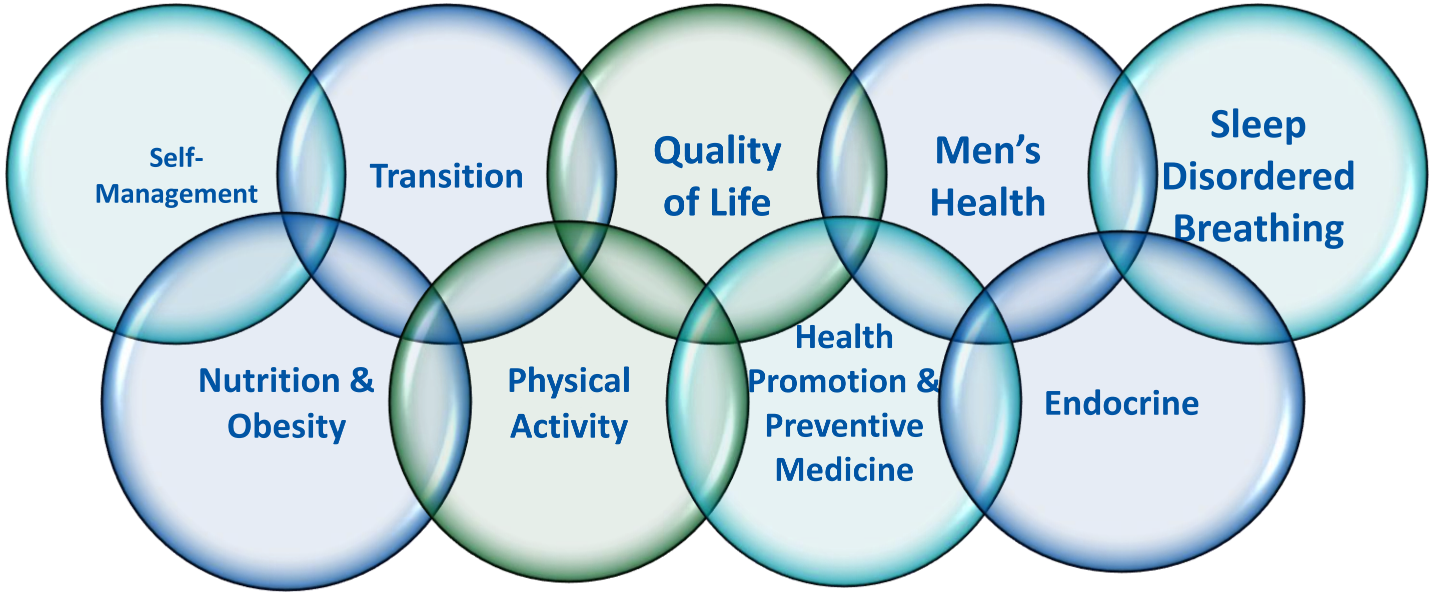
- 9 new topic areas suggested:



Self-Management

Transition

Quality of Life

Men's Health

Sleep Disordered Breathing

Nutrition & Obesity

Physical Activity

Health Promotion & Preventive Medicine

Endocrine

Oversight

- Medical Director
  - Tim Brei
- Steering Committee Co-Chairs
  - Pat Beierwaltes
  - Brad Dicianno
  - Nienke Dosa
- Patient Advisory Group
- Executive Committee
  - Sara Struwe
  - Judy Thibideau
  - Julie Bolen
  - Adrienne Griffin
  - Lisa Raman
  - Jerome Chelliah
- 24 Working Group Chairs
  - Working Group members
- CDC Staff
- SBA Staff and Students

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Methodology

- Recognized consensus-building methodologies for the development of clinical practice guidelines
  - Single Text Procedure
  - Nominal Group Technique
- More than 80 experts participated in the process
- Multi-disciplinary groups
- Spans newborn to adult
- For both SB providers and PCPs

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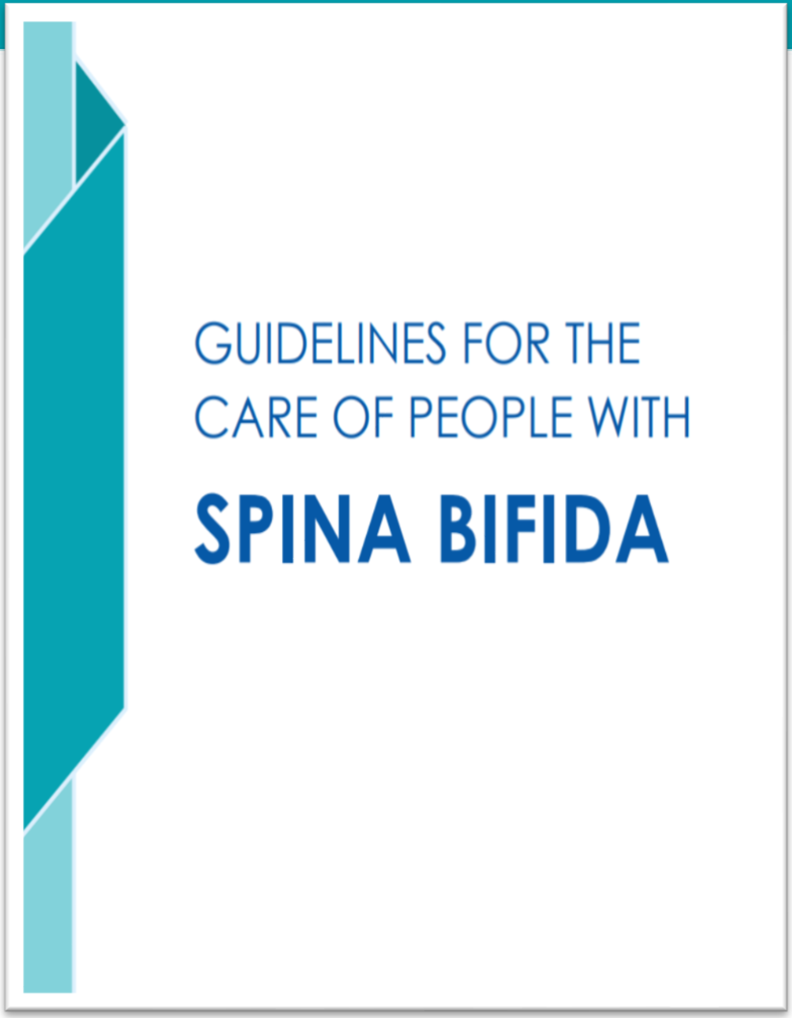
Format

- Outcomes – what we wish to achieve with good care
- Clinical questions – important questions that were targets of the lit review
- Guidelines – recommendations for care that are based on the lit review and clinical consensus
- Research gaps – important topics where research and clinical consensus are lacking
    - Synergistic areas with NSBPR

Healthcare Guidelines Updates

- 2018 Guidelines for the Care of People with Spina Bifida
  - https://www.spinabifidaassociation.org/resource/guidelines/
- Methodology
  - Dicianno BE, Beierwaltes P, Dosa N, Raman L, Chelliah J, Struwe S, Panlener J, Brei T. **Scientific Methodology of the Development of the Guidelines for the Care of People with Spina Bifida: An Initiative of the Spina Bifida Association**. Disability and Health J. In press.



GUIDELINES FOR THE
CARE OF PEOPLE WITH
SPINA BIFIDA

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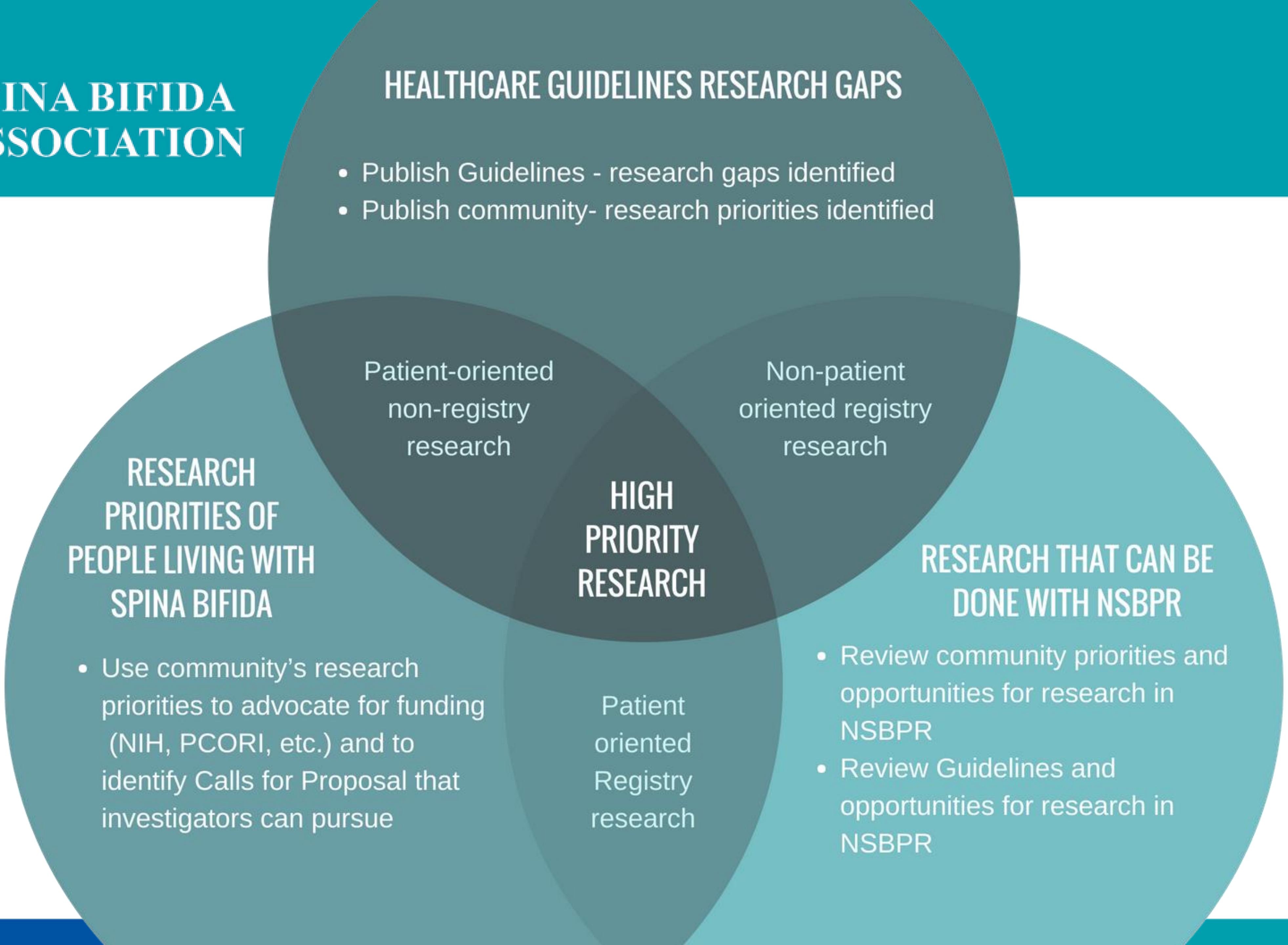


HEALTHCARE GUIDELINES RESEARCH GAPS

- Publish Guidelines - research gaps identified
- Publish community- research priorities identified

Patient-oriented non-registry research

Non-patient oriented registry research

RESEARCH PRIORITIES OF PEOPLE LIVING WITH SPINA BIFIDA

- Use community's research priorities to advocate for funding (NIH, PCORI, etc.) and to identify Calls for Proposal that investigators can pursue

HIGH PRIORITY RESEARCH

Patient oriented Registry research

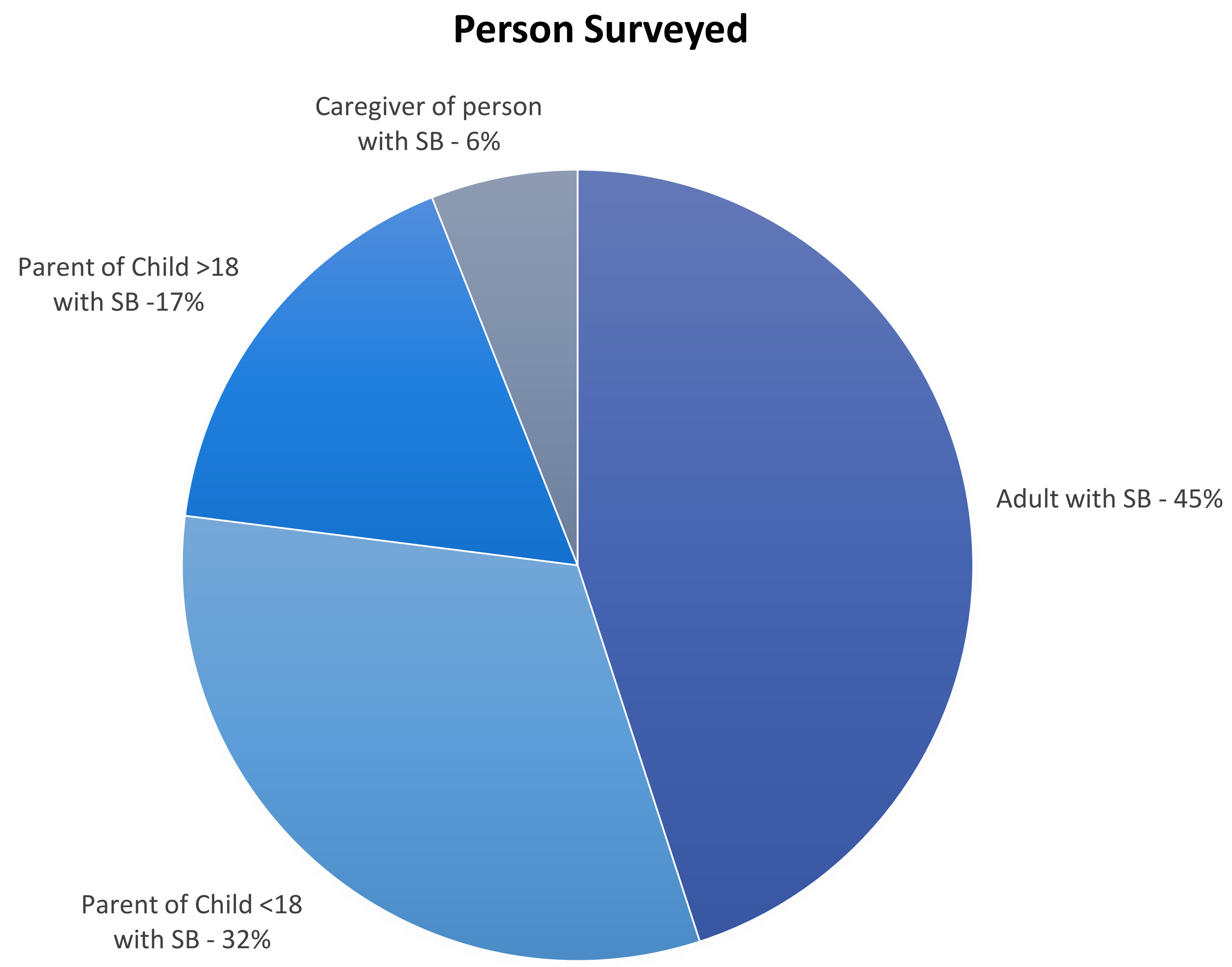
RESEARCH THAT CAN BE DONE WITH NSBPR

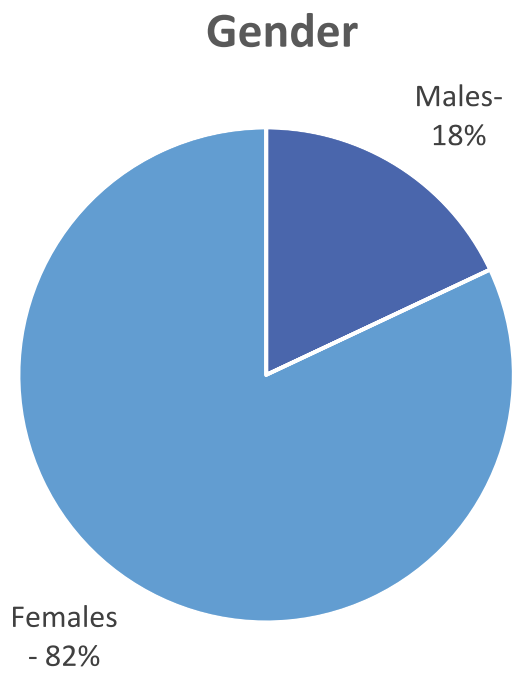
- Review community priorities and opportunities for research in NSBPR
- Review Guidelines and opportunities for research in NSBPR

Survey Methodology

- Online survey
  - Emailed survey link to SBA database of +/-20,000, and posted on SB Facebook pages April/May, 2019
  - Survey was offered in English and Spanish
- 1717 total responses
  - 1,607 among “qualified respondents” (parents of children under and over 18 with SB, adults with SB, and caregivers of person with SB)
- Follow up focus groups conducted in May, 2019 during Teal on the Hill event
  - Parents of child with SB, and Adults with SB

Respondent Characteristics





27 Items Evaluated

Accessing Coordinated Care b/w PCPs & Specialists	Leg/Foot Deformities	Difficulty Breathing due to side effects of SB: Chiari II or Scoliosis
Finding Doctors who care for Adults/Children with SB	Skin Breakdown	Managing Preventable Health Conditions to Avoid ER Visits
Obstructive Sleep Disorders /Sleep Apnea	Urinary Incontinence	Managing Chiari II Symptoms/Consideration Surgical Options
Encourage Self-Management Behaviors in Children	Urinary Tract Infections	Shunt Insertion/Complications
Independence/Ability to Care for Oneself	Bowel Incontinence	Management/Care related to Tethered Cord
Ensuring Daily Physical Activity	Menopause/Women’s Health Issues	Learning Disabilities
Mobility	Prenatal Counseling for Women	Depression/Mental Health
Pain Related to Mobility	Prostate Cancer Screening/ Treatment	Managing Weight/Nutrition
Use of HGH/Human Growth Hormone	Early Onset of Puberty	Having an Active Sex Life

Questions

How much of an issue is__________________

- A very big issue
- Somewhat of an issue
- Not much of an issue
- Not an issue at all

Question

*Choose up to 5 items from the list below that are the biggest issues or concerns you have about living with Spina Bifida.**

*Respondents were provided previous list of items; order of items were rotated for each respondent

Top 5 Biggest Issues/Problems Overall*

% Citing Each Item as one of 5 Biggest Issues: Top Mentions

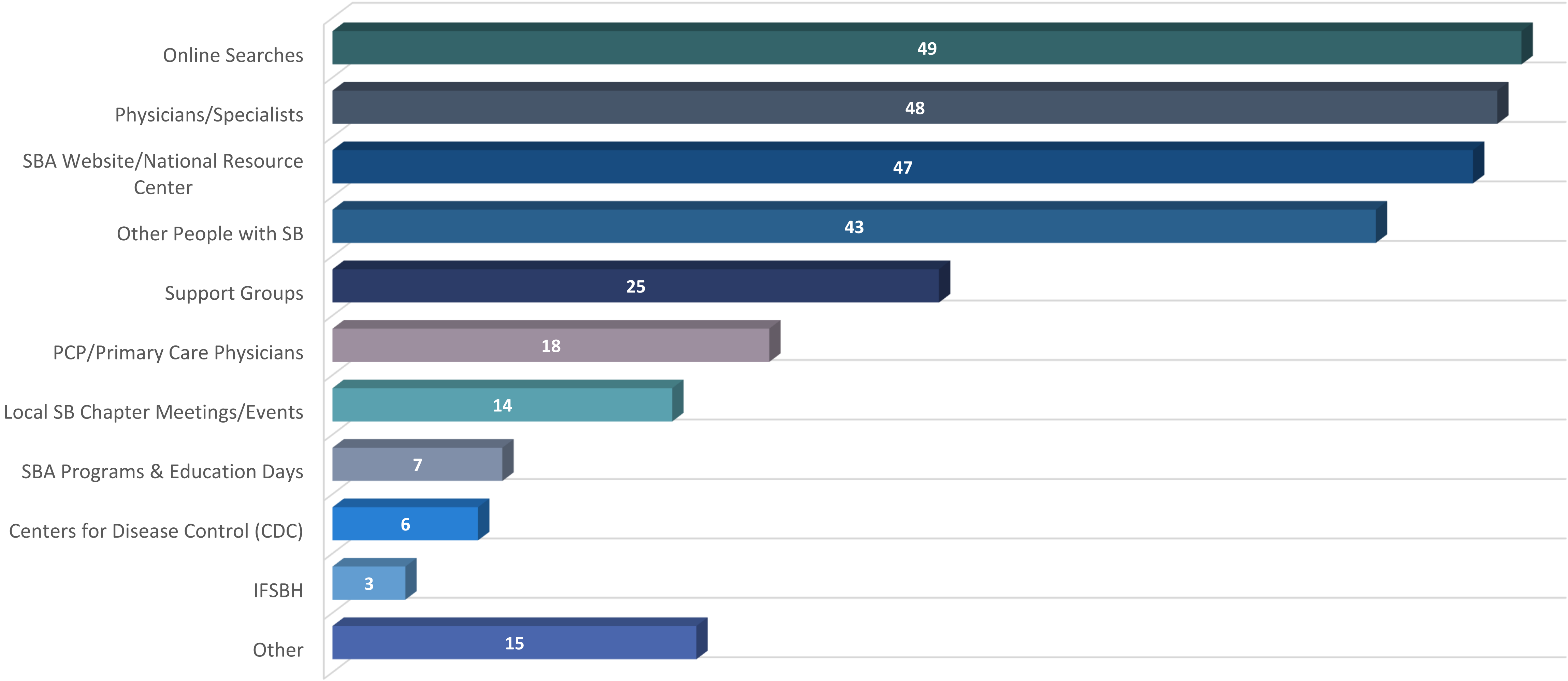
Parents of Child <18 with SB	%	Parents of Child > 18 with SB	%	Adults with SB	%
Bowel Incontinence	64	Finding Doctors	50	Finding Doctors	55
Urinary Incontinence	51	Bowel Incontinence	49	Bowel Incontinence	51
Independence	50	Independence	44	Managing Weight	44
Encourage Self Mgt	48	Managing Weight	40	Urinary Incontinence	43
Learning Disabilities/Attention Disorders	41	Learning Disabilities/Attention Disorders	32	Depression/Mental Health	42

*Multiple responses

Qualitative Survey Results

- Respondents were asked to mention any *other/additional* issues that were problems for themselves or their children with SB. Some of the areas mentioned included:
  - Issues related to out-of-pocket expenses and items not covered by insurance
    - Medical supplies
    - Medical equipment
    - Mobility equipment
  - Not enough SB clinics for adults, or physicians with SB expertise
  - Transitioning from pediatric to adult care
  - Employment/jobs for people with SB
  - Socialization opportunities for children and adults with SB

How or where do Adults/Parents get information about SB?*



*Multiple responses

Breakouts

- Bowel Management
- Nutrition, Obesity & Metabolic Syndrome
- Mobility & Orthopedics
- Urology
- Neuropsychiatry & Neurosurgery
- Skin Breakdown

Ongoing and New Research Opportunities

- Effects of medications and bowel interventions on continence
- Effects of a defined bundle of prevention strategies on skin breakdown
- Accurate assessment of body composition, growth curves and weight classification
- Relationship between continence and quality of life
- How do patients define continence?
- Is there a “threshold” for social continence? Quantity vs. Frequency.
- What orthopedic issues/surgeries affect mobility outcomes?
- Relationships between neurosurgical interventions and neuropsych outcomes

Spina Bifida Adults/Parents Survey

Questions & Comments

Respondent Demographics

Age of Person >18 with SB*	%	Age of Child <18 with SB	%
18-24	17	0 - 11 months	**5**
25-34	25	1 - 2 years	**10**
35-44	28	3 - 5 years	**19**
45-54	16	6 - 12 years	**45**
55-64	10	13 - 17 years	**21**
65+	4		
Total	100%	Total	100%

*Includes Adults with SB and Adult Children >18 with SB

Respondent Demographics (continued)

Education	%
Less than High School	2
HS Graduate	12
Technical/Trade School	4
Some College/2-year degree	28
College Degree (BA. BS)	32
Master’s/PhD	21
Total	100%

Race/Ethnicity*	%
African American/Black	3
Caucasian/White	87
Asian American/Asian	2
American Indian/Alaskan Native	1
Native Hawaiian/Pacific Islander	<1
Multi Racial	3
Other/DK	7
***Multiple responses**	
Total	100%
Hispanic/Latino	10